



State of Rhode Island and Providence Plantations GUBERNATORIAL PROCLAMATION

Rare Disease Day

WHEREAS, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

WHEREAS, while approximately 340 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people according to the Food and Drug Administration, that leaves well over 15 million Americans with rare diseases who have no treatment specific to their disease; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

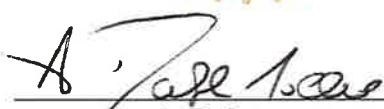
WHEREAS, some rare diseases, such as "Lou Gehrig's disease" and Huntington's disease, are relatively well known, many others are not known at all by the public so that patients and their families must bear a large share of the burden for things such as raising funds for research; and

WHEREAS, thousands of residents of Rhode Island are among those affected by rare diseases since nearly one in 10 Americans have rare diseases; and


WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on the last day in the month of February each year and patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases are joining together to focus attention on rare diseases as a public health issue on that day; and

NOW, THEREFORE, I, Lincoln D. Chafee, Governor of the State of Rhode Island and Providence Plantations, do hereby proclaim February 28, 2013 as Rare Disease Day and encourage all residents to recognize the importance of this day.




A. Ralph Mollis
Secretary of State

Given under my hand and the great
seal of the State of Rhode Island
and Providence Plantations,
this 31st day of January, 2013


Lincoln D. Chafee
Governor